CHECK’D?! : determinants of participation in a two-stage cardiometabolic screening among underserved groups

Groenenberg, I.

Citation

Groenenberg, I. (2017, May 11). *CHECK’D?! : determinants of participation in a two-stage cardiometabolic screening among underserved groups*. Retrieved from https://hdl.handle.net/1887/48563

Author: Groenenberg, Iris
Title: CHECK'D?! : determinants of participation in a two-stage cardiometabolic screening among underserved groups
Issue Date: 2017-05-11

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‘Check it out!’ Decision-making of vulnerable groups about participation in a two-stage cardiometabolic health check: A qualitative study

Iris Groenenberg[1], Mathilde R. Crone[1], Sandra van Dijk[1], Winnifred A. Gebhardt[2], Jamila Ben Meftah[1], Barend J.C. Middelkoop[1], Anne M. Stiggelbout[1], and Willem J.J. Assendelft[1,3]

[1] Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, the Netherlands.
[2] Department of Health, Medical, and Neuropsychology, Leiden University, Leiden, the Netherlands.
[3] Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, the Netherlands.

Patient Education and Counseling *(2015), 98(2): 234–244*

ABSTRACT

Objective

Exploring determinants influencing vulnerable groups regarding (non-)participation in the Dutch two-stage cardiometabolic health check, comprising a health risk assessment (HRA) and prevention consultations (PCs) for high-risk individuals.

Methods

Qualitative study comprising 21 focus groups with non-Western (Surinamese, Turkish, Moroccan) immigrants aged 45–70, adult children from one of these descents, native Dutch with a lower socioeconomic status, and healthcare professionals working with these groups.

Results

Reasons for not completing the HRA included (flawed) risk perceptions, health negligence, (health) illiteracy, and language barriers. A face-to-face invitation from a reliable source and community outreach to raise awareness were perceived as facilitating participation. Reasons for not attending the PCs overlapped with completing the HRA but additionally included risk denial, fear about the outcome, its potential consequences (lifestyle changes and medication prescription), and disease-related stigma.

Conclusion

Reasons for not completing the HRA were mainly cognitive, whereas reasons for not attending the PCs were also affective. Practice implications: when designing a two-stage health check, choice of invitation method seems important, as does training healthcare professionals in techniques to effectively handle patients' (flawed) risk perceptions and attitudinal ambivalence. Focus should be on promoting informed choices by providing accurate information.

INTRODUCTION

In most Western countries (including The Netherlands) mortality and morbidity of cardiovascular disease, diabetes, and kidney failure are higher for people with a lower socioeconomic status (SES) and for non-Western immigrants (1, 2). Moroccan, Turkish, and especially Hindustani Surinamese immigrants are at higher risk of developing diabetes (3). Prevalence of cardiovascular disease is particularly high in the latter two groups (4–6). Health checks are currently implemented to identify those at increased risk of cardiometabolic disease (CMD) (7–9). However, individuals participating in health checks are more often health-conscious, higher-educated, affluent people (10, 11). Participation is lower among people with a heightened risk, e.g. individuals of non-Western descent or with a lower SES (12). Few studies specifically investigated (non-)participation in cardiometabolic health checks of non-Western immigrants or lower SES groups. The literature mostly concerns (non-)attendance in cancer screening or cardiometabolic screening in the general population (13–16). Results from studies on cancer screening might provide reasons for (non-)participation generalizable to cardiometabolic screening. However, risk perceptions and beliefs regarding cancer differ from those regarding CMD: perceived risk and worries are higher for cancer than for CMD (17). Thus, more insight into determinants of (non-)participation in a cardiometabolic health check is needed, specifically among vulnerable groups to enable them to make an informed decision about participation. Several studies concluded that a two-stage approach could be a cost-effective screening strategy for cardiometabolic risk (18, 19). The Dutch cardiometabolic health check follows a two-stage approach and comprises a short risk stratification tool (health risk assessment: HRA) for people aged 45–70 years, and two prevention consultations (PCs) including a blood test with the GP for those at increased risk according to the HRA. During the PCs patients receive information about their risk profile, followed by lifestyle advice and, if necessary, medication prescription. However, this approach implies that patients can refrain from participation on two separate occasions, which may represent an even greater problem among difficult-to-reach groups. Indeed, pilot studies showed substantial dropout rates in both stages (20). In-depth research focusing on determinants related to (not) completing a HRA and (non-)participation in subsequent PCs separately is scarce. Moreover, vulnerable groups require special attention. Therefore, this study investigates which informational, practical, and psychosocial determinants influence the decision of different vulnerable groups to (not) participate in the HRA and the PCs.

METHODS

Sample and recruitment

This study was approved by the Medical Ethical Committee of the Leiden University Medical Center (CME-09-126). Participants' verbal informed consent was audio-taped. Purposive sampling by key persons was used to conduct focus groups with non-Western immigrants (45–70 years, except Surinamese: 35–70 years because of their higher diabetes risk); adult children of non-Western immigrants (18–45 years); lower SES native Dutch (45–70 years); and health professionals working with the target population. Key persons (educational coordinators and managers or employees of community/cultural organizations or local community health services) were well-known persons within a community who used their status and contacts to recruit people willing to participate. Potential participants were approached by e-mail, telephone, or face-to-face, and we also made use of flyers and posters, distributed mainly in colleges and secondary vocational education institutes. The rationale for also conducting focus groups with health professionals was their ample experience with the target population in relation to health (screening) initiatives and their ability to reflect on what would (not) work, and why. Health professionals were recruited through our network for primary care research in which 90 regional general practices work together in scientific research. Focus groups were held separately for each ethnic group. For immigrants, focus groups were purposively held separately for males and females. The rationale for also conducting focus groups among adult children of immigrants was that they usually have a better command of the Dutch language and frequently act as brokers for their parents in the Dutch healthcare system. Two focus groups were held in each subgroup. Due to the large number of subgroups, it was not possible to use data saturation as a criterion for individual subgroups. However, by combining results from the adult children, immigrants, native Dutch, and health professionals, we reached saturation on group level. Focus group characteristics are presented in Table 1.

Table 1. Characteristics of the focus groups

Group	No. of focus groups	No. of participants	Location/recruitment
Immigrants			
Turkish	1♂ ; 1♀	5 ; 10	Turkish associations
Moroccan	1♂ ; 1♀	10 ; 8	Community organisation
Hindustani	1♂ ; 1♀	7 ; 8	Community organisation
Creole	1♂ ; 1♀	5 ; 7	Community organisation
Adult children			
Turkish	1♂ ; 2♀	7 ; 7 ; 8	Senior secondary vocational education and Turkish activity centre
Moroccan	2♀	2 ; 8	Senior secondary vocational education and higher professional education
Hindustani	1♂♀	4	Higher professional education
Creole	1♂♀	2	Higher professional education
Mix[a]	1♂♀	4	Senior secondary vocational education
Dutch lower socio-economic status	1♂ ; 1♀ ; 1♀♂	4 ; 5 ; 8	Community health service and general practice
Health professionals	2♂♀	3 ; 3	General practices

♂ Focus group held with males. ♀ Focus group held with females. ♂♀ Focus group held with both males and females.
[a] Hindustani and Creole.

Data collection

Focus groups were held between February and July 2010 at locations familiar to participants, where they felt safe and at-ease. All focus groups with immigrants and one with adult children were performed at their own community/cultural organizations, during the evening. The other focus groups with adult children were held at their educational institution during free hours between classes. One focus group with native Dutch was held at a community health service where the participants regularly attended recreational activities or health classes, the other was held at the participants' own general practice, both around lunch time. The focus groups with health professionals were held at the research center. One female researcher (IG) was trained to be facilitator and another female researcher (MC) was observer/notetaker. During focus groups at community/cultural organizations a female staff member of the same ethnic background was observer/notetaker. Focus groups were held primarily in Dutch, were audio-taped, and lasted 1–2 h. The observer/notetaker translated when participants did not speak Dutch or preferred to speak in their native language. The interview protocol was pilot tested with members of our target population and consisted of two parts (see Appendix for an example protocol). First, HRA invitation strategies and determinants influencing HRA participation were discussed. Second, risk communication and determinants influencing PCs participation were discussed. The interview protocol was based on the constructs from the Integrated change model (I-change model) (Fig. 1), which has been applied in studies on screening attendance and smoking behaviour in native and immigrant populations (21–24). The I-change model aims to explain health behaviours and incorporates elements from health behaviour theories such as the Health Belief Model (25), Protection Motivation Theory (26), Theory of Planned Behaviour (27), and Precaution Adoption Process Theory (28). The model states that behaviours are determined by a person's motivation or intention to carry out a behaviour and is the result of a person's intentions, abilities, and barriers. Attitudes, social influences, and self-efficacy expectations influence a person's motivation and are determined by various distal factors, such as predisposing (e.g. current lifestyle), information (e.g. source of delivery), and awareness (e.g. knowledge) factors. The rationale for choosing this model was that health check attendance could be seen as a health behaviour and in that sense be studied with this comprehensive model.

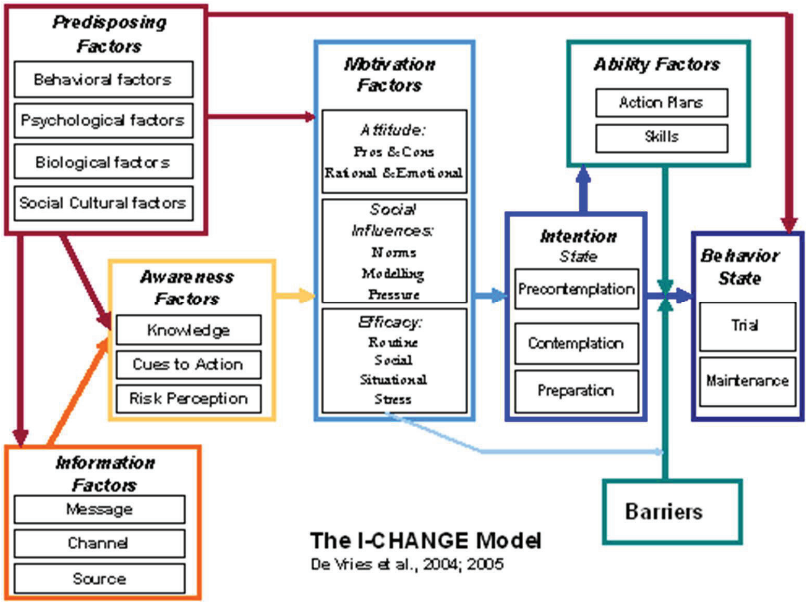

Figure 1. The I-change model, from http://www.maastricht-university.eu/hein.devries/interests/change

Data analysis

Audio-tapes were transcribed verbatim. The remarks of the participants without command of the Dutch language were transcribed and translated by the ethnicity-matched observer. Data analysis was done on all focus group transcripts combined and facilitated by Atlas.ti 6.2 software. Most coding was performed deductively with codes based on the determinants of the I-change model, and partly inductively when a new code emerged. To increase reliability, coding was independently performed by two researchers (IG and MC) until consensus was reached, which was after five interviews (29, 30). After this, the other transcripts were coded by IG and only discussed with MC in case of doubt about the appropriate code. Alike the codes, themes were partly identified in advance and partly derived from the data. Thematic content analysis (including merging or subdividing codes and allocating to themes) was performed by IG and MC and validated among members of the research team (WA, AS, SvD, and WG) until consensus was reached.

RESULTS

Demographics

In total, 125 participants took part in the focus groups, of whom 119 filled out the background information questionnaire. Table 2 presents these participants characteristics. Many Surinamese participants were retired and participants in the other groups were often unemployed or disabled. Female participants mainly reported housekeeping as their occupation in daily life. The majority of the adult children (mainly female) combined their education or job with housekeeping.

Table 2. Characteristics of the participants in the focus groups (n=119)

Group	Mean age, in years (±SD)	Married, n (%)	Religious, n (%)	Occupation in daily life[b], n (%)			
				Education	Job	Retired	Household
Immigrants							
Turkish (n=15)	52 (± 8.5)	13 (87%)	15 (100%)	NA	1 (7%)	1 (7%)	6 (40%)
Moroccan (n=18)	54 (± 6.8)	18 (100%)	18 (100%)	NA	1 (6%)	1 (6%)	8 (44%)
Hindustani (n=15)	62 (± 12.4)	9 (60%)	13 (87%)	NA	0 (0%)	7 (47%)	6 (40%)
Creole (n=12)	64 (± 7.6)	3 (25%)	12 (100%)	NA	2 (17%)	9 (75%)	1 (8%)
Adult children							
Turkish (n=22)	34 (± 13.4)	13 (59%)	17 (77%)	9 (41%)	12 (55%)	NA	5 (23%)
Moroccan (n=10)	19 (± 3.6)	1 (10%)	9 (90%)	10 (100%)	4 (40%)	NA	3 (30%)
Hindustani (n=4)	21 (± 1.4)	0 (0%)	2 (50%)	4 (100%)	2 (50%)	NA	2 (50%)
Creole (n=2)	25 (± 5.0)	0 (0%)	1 (50%)	2 (100%)	0 (0%)	NA	0 (0%)
Mix[a] (n=4)	19 (± 1.5)	0 (0%)	4 (100%)	4 (100%)	1 (25%)	NA	1 (25%)
Dutch low SES (n=17)	61 (± 11.4)	13 (77%)	10 (59%)	NA	2 (12%)	4 (24%)	4 (24%)

NA: Not applicable. [a] Hindustani and Creole. [b] Multiple answers possible

Methods of invitation

Information factors

A personal invitation for participation in the HRA during a GP or home visit was preferred to an invitation by letter, telephone, or online. Face-to-face contact was believed to result in more reliable results because people would receive practical help and be more honest. Additionally, it was thought to be a useful way of spending time in the waiting room. The GP was seen as a reliable source. Nevertheless, a good relationship and trust were considered essential for participation. Participants emphasized the importance of regional/national publicity and repetition regarding the availability of the HRA to get acquainted with it and for branding to occur. It was proposed to notify people in advance that they would soon receive an invitation, to provide reminders, and to make use of social networks for word-of-mouth publicity.

Determinants regarding participation in the HRA

Tables 3 and 4 present an overview of reasons respectively decreasing and increasing the likelihood of participation in the HRA. Reasons are categorized under I-change constructs and more specific determinants. Ethnic group(s) for whom the reason was most prominent is mentioned, as well as a detailed description of the reason, with an illustrative quote for a selection of reasons.

Predisposing factors

Participants believed that women would be more likely to participate than men. A lack of physical symptoms would be a reason for some to participate (Quote 1.2, Table 4), whereas for others it would not. Already having a disease made participants more prone to participate, as would a family history of CMD. An exception were the Hindustani participants (a group genetically predisposed to CMD), who expressed the view of Hindustanis being more passive in general (Quote 1.3, Table 3). Passiveness was not expressed as a typical group trait among other ethnicities, but was recognized as an individual trait affecting participation (i.e. being lazy/lax). Dissatisfaction with the Dutch healthcare system was a reason for many Turkish and Moroccan participants to prefer a health check in their home country.

Table 3. Summary of determinants decreasing the likelihood of participation in the HRA

Construct	Determinant	Ethnicity[a]	Description		Quote
1.Predisposing factors	1.Gender; male	A	More stubborn, selfish, and careless about their health	➔	Quote 1.3 on family history (Surinamese adult child): *“Usually they often say: ‘it runs in our family so I’ll get it all too. Whether I’ll fill it out or not, I’ll get it anyway’. Because on my dad’s family’s side somebody has diabetes and on my mom’s side…so they would think: ‘I’ll get it, whether I’ll fill it out or participate or not, I’ll get it anyway’.”*
	2.Symptoms; not present	A	Feeling healthy, thus not seeing the need to screen for cardiometabolic disease		
	3.Genetics; family history	S	High awareness of family history of cardiometabolic disease among Hindustani, yet burying their heads in the sand		
	4.Passiveness/laziness	A/S	Not showing up, not being interested, not participating, especially among Hindustani		
	5.Comparison health care home country	T/M	Perceived less expensive and better care, more in-depth testing, and faster results in home country		
2.Awareness factors	1.Health illiteracy	A	People with little or no education are more ignorant concerning health and disease	➔	Q 2.2 on unrealistic risk estimation (Dutch lower SES): *“Because unconsciously you think: ‘I live healthy right? I don’t smoke, I exercise’, while you’re eating a nice and fat meal you think: ‘damn, I live healthy right? I eat well’.”*
	2.Risk estimation; unrealistic	A	Unrealistically optimistic evaluation of lifestyle, incorporating facts and emotions, or a perceived lower risk than that of others		
3.Motivation factors	1.Attitude; negative	D A	Aggressiveness, ‘none-of-your-business-attitude’ Disadvantages of participation: poor outcome and confrontation	➔	Q 3.3 on fear (Health professional): *“I’m afraid that if you motivate people based on their fear, at a certain point in time this fear will subside and they’ll think: ‘whatever, never mind’. I don’t believe in this. Concerning health, especially prevention, it’s best to be positive. A negative approach…no I don’t think that will be the way to hold on to people.”*
	2.Attitude;indifference	A	Nonchalance, not feeling like it		
	3.Fear	A	Anticipated fear of a poor outcome, disease, death, doctors, medication, and lifestyle changes		
	4.Social influences	A	The unimportance of participation as norm within the community, the (expected) unimportance that significant others would place on one’s participation (subjective norm), the (expected) non-participating behavior of significant others (descriptive norm or modeling), negative conversations, and pressure. Important others were mainly children, other family members, a confidant such as the GP or a key person within the community, friends, or neighbors		
	5.External locus of control	D/S T/M	External causes of disease, or destiny A God causing disease		
4.Barriers and ability factors	1.Illiteracy	A	Too extensive and too complicated making participation difficult, especially for illiterate people, or people who have had little or no education	➔	Q 4.2 on language barriers (Turkish immigrant): *“Look: I’m Turkish and I’ve got the Dutch and Turkish nationality. I can read a bit of Dutch and speak normally. But if I see a form, I don’t understand half of it, to fill it out precisely and accurately. My kids speak better Dutch than Turkish. If I ask them to fill out a form in Turkish, they can’t do it because they are not good in Turkish.”*
	2.Language barrier	T/M	Little or no command of Dutch language		
	3.No action linkage children	D/S	Rather toss HRA aside than ask for help		
	4.Costs	D	Possible costs of cardiometabolic screening		

[a] Column represents the ethnic group(s) in which determinant was most prominent: A=all groups, T=Turkish, M=Moroccan, S=Surinamese, D=Dutch

Awareness factors

Completing the HRA would be too difficult for some due to health illiteracy, i.e. they would be less able to understand the HRA and its accompanying information on CMD. Many participants were aware of health checks being offered for a variety of health conditions by various sources. Previous experience with a health check would not make participants more reluctant to participate, provided that it concerned a different health condition (Q 2.1, Table 4). It was believed that many people would not participate while feeling less at risk than others. They would compare their own perceived healthy lifestyle with that of others and, possibly unrealistically, would conclude that participation would not be useful for them (Q 2.2, Table 3). Simultaneously, it was presumed that many participants desired a sense of certainty about their risk status, even when they believed that they had a low risk.

Motivation factors

Most participants had a positive attitude and elaborated on the advantages of participating. Nevertheless, participants knew many people who would have a negative or indifferent attitude. Although fear of being ill was deemed important, participants (especially the healthcare professionals) considered it wrong to deliberately use fear as a motivational strategy (Q 3.3, Table 3). This could make people more afraid of the outcome and the possible consequences of a high-risk status (i.e. having to make lifestyle changes). Although participants tended to be reluctant admitting this, social influences seemed to play a major role in the decision-making, both emotionally and practically. For example, some participants were afraid that the test results would be known by others besides the GP who would then know that they were ill and, consequently, would judge or mistreat. Encouraging would be having family members or important others advising them to participate or participating themselves (Q 4.2, Table 4). Sometimes, participation seemed unnecessary for patients who believed in a God or other external influences causing disease (i.e. external locus of control).

Table 4. Summary of determinants increasing the likelihood of participation in the HRA

Construct	Determinant	Ethnicity[a]	Description		Quote
1.Predisposing factors	1.Gender; female	A	More health conscious, aware, and actively engaged in their health	➔	Q 1.2 on symptoms not present (Surinamese immigrant): *"Yes, that's what I always say: you're walking ill. You live but you're ill from the inside. Till it erupts you don't know that you're ill, but it has already started, maybe from a young age. But because you didn't know or you didn't go to the GP, you let it be. People should be convinced: 'Even though I feel like a bear who can conquer the world, something might potentially be present, so let's do that check'."*
	2.Symptoms; not present	A	Realization one might still have an increased risk of cardiometabolic disease or be ill already		
	3.Symptoms; present	A	More health conscious, more serious		
	4.Genetics; family history	A	Family history of cardiometabolic disease makes people more aware and more likely to participate		
	5.Comparison health care home country	S	Wish for health care system in Surinam to be more like the prevention focused system in the Netherlands		
2.Awareness factors	1.Prior experience	A	Prior experience with a health check does not make participants more reluctant to participate provided that it concerns a different disease	➔	Q 2.1 on prior experience (Surinamese adult child): *"He does check-ups now regularly too, so I don't know if this is really something different, but if it is something different he would do it for sure."*
	2.Risk estimation; sense of certainty	A	Reason to screen is more certainty about risk status: knowing whether you are at high risk or not		
3.Motivation factors	1.Attitude; positive	A	Advantages of participation: health benefits, future, sense of certainty, importance, interesting, no harm could result	➔	Q 3.2 on social influences (Moroccan adult child): *"That you let an Imam or so say: 'Oh guys, think about that test. Don't forget to fill it out!'."*
	2.Social influences	A	The importance of participation as norm within the community, the (expected) importance that significant others would place on one's participation (subjective norm), the expected participating behavior of significant others (descriptive norm or modeling), positive conversations, pressure, and support. Important others were mainly children, other family members, a confidant such as the GP or a key person within the community, friends, or neighbors		
4.Barriers and ability factors	1.Textual adjustments	A	Formulate as concisely and simply as possible, limit number of questions, keep overall level of difficulty to a minimum	➔	Q 4.2 on children as action linkage (Moroccan adult child): *"And truthfully, for my mom it depends on whether we have time for it because she doesn't speak Dutch, so she's always dependent on us. First, they'll call for me, probably I'm in the middle of doing something fun in my room. 'THERE'S A LETTER!', well then I'll read it. They'll make sure it gets filled out by one of the children."*
	2.Action linkage children	T/M	Children as translators		
	3.Compensation in costs	A	Participation for free, providing a self-addressed envelope or stamp, and possibly a small present		

[a] Column represents the ethnic group(s) in which determinant was most prominent: A=all groups, T=Turkish, M=Moroccan, S=Surinamese, D=Dutch

Barriers and ability factors

Participants usually found questionnaires and invitation letters too extensive and complicated. It was strongly advised to formulate these texts as concisely and simply as possible. Because Turkish and Moroccan participants also faced a language barrier (Q 4.2, Table 3), in many families the children would translate (Q 4.2, Table 4). Among Surinamese and Dutch participants it was not common to ask the children for help. Finally, especially among the Dutch groups, it was emphasized that participation would be free. Summarizing, reasons for not completing the HRA were mainly cognitive and included rational cost–benefit considerations incorporating (flawed) risk perceptions, health negligence, (health) illiteracy, and language barriers.

Risk communication

Information factors

The message of a high-risk HRA result should be formulated simply and briefly, but not too directly and information about its consequences should be provided. Surinamese and Dutch participants felt strongly about the voluntary nature of PCs participation. Consequently, providing a prescheduled date for the appointments would have adverse effects. The ensuing face-to-face contact and physical examinations during the PCs made the relationship between the participants and their GP even more important. They felt that the GP should be reassuring and make an effort to come to them, i.e. into the community.

Determinants regarding participation in PCs

Tables 5 and 6 present an overview of (additional) determinants respectively decreasing and increasing the likelihood of participation in the PCs.

Predisposing factors

Similar predisposing factors mentioned for HRA (non-)participation were raised again when discussing the PCs. An additional factor mentioned was that the older generation would be more likely to visit their GP than the younger generation (Q 1.1, Table 6). However, at a certain age (i.e. around 70 years) people would not see the point of prevention anymore (Q 1.1, Table 5).

Table 5. Summary of (additional) determinants decreasing the likelihood of participation in the PCs

Construct	Determinant	Ethnicity[a]	Description		Quote
1.Predisposing factors	1.Generation differences; oldest generation	A	Not seeing the use of going to a doctor for prevention anymore	➔	Q 1.1 on generation differences (Dutch lower SES): “*But at a certain point in time, he was 78 years old, my father in law said: ‘I’m not interested anymore, never mind’.*”
2.Awareness factors	1.High risk test result	A	‘License to misbehave’	➔	Q 2.1 on high risk test result (Surinamese immigrant): “*I think there are people who think: ‘oh, an increased risk, okay, I won’t go to the GP, I’m okay with it, I’m not going to follow a diet, I’m going to live and I’ll see how it goes.’ I think, they see it to some extent as: now is the chance to live my life to the fullest.*”
3.Motivation factors	1.Fear	A	Fear: caused by the risk communication, of confirmation of risk status or diagnosis of disease during PCs, of the GP or doctors in general, of treatment and/or medication, of lifestyle changes		
	2.Fatalism	A	Feeling of helplessness, feeling that one will get the disease and die anyway, that time has inevitably come	➔	Q 3.2 on fatalism (Turkish immigrant): “*After 50, Turkish females don’t function anymore, somehow they don’t want to anymore. They do want to live but they say: ‘Our kids are grown up, we’re old, yes it’s time for us, we retreat. It’s time for us to go to the other side’.*”
	3.External locus of control	A	External causes, faith, or a God causing disease, making participation pointless		
	4.Convictions; ‘guinea pig’	T	Feeling of being treated like a guinea pig, leading to denial and distrust in research and the Dutch health care system		
	5.Gossip	T/M	About high-risk test result, but more so what would be discussed during PCs and possible diagnosed disease. An ethnicity-matched translator would encounter suspicion out of fear that (s)he would not keep things from the community		
4.Barriers and ability factors	1.Health illiteracy and language barrier	A T/M	Difficulty of information provided and translation barriers, leading to mistakes and misunderstandings		
	2.Money concerns	A	Concerns whether PCs, including lab work, would be covered by insurance. Costly consequences of PCs: medication or other treatment, and lifestyle changes		
	3.Time concerns	D T/M	Getting free from work (office hours GP). Prolonged absence during holidays + Ramadan, leading to reluctance or prohibition to participate, the latter mainly because of the physical tests	➔	Q 4.3 on time concerns (Health professional): “*The boss won’t allow it, for men that’s a common problem. Being ill is for your spare time. Then they won’t participate, well maybe your mere loyal soul but the vast majority will fall out obviously. And don’t organize it during the wrong period of time: never during summer holidays and never during Ramadan. Right before or right after Ramadan isn’t a good idea either. Actually, you’ve got pretty little time left.*”

[a] Column represents the ethnic group(s) in which determinant was most prominent: A=all groups, T=Turkish, M=Moroccan, S=Surinamese, D=Dutch

Awareness factors

An important cue to action would be the confrontation with an unfavourable test result (Q 2.1, Table 6), after which many would go to the PCs to gain more certainty about their risk and disease status. However, some would not go and might use a high-risk status as a 'license to misbehave' (Q2.1, Table 5). According to the participants, these people might think that it would no longer be necessary to put much effort into behaving healthily as they already have a high risk.

Motivation factors

Participants believed that many would be convinced of the necessity of screening after receiving a high-risk HRA result (Q 3.1, Table 6). However, they also believed that for some an increased risk would come as such a shock that they would not believe it. Participants thought that fear would be so strong that it would translate into helplessness or fatalism (Q 3.2, Table 5). Also, an external locus of control played a role in the perceived pointless-ness of participation. Among the Turkish groups, a feeling of being treated like a 'guinea pig' was common. Notable was the more prominent role of gossip, especially among the Turkish and Moroccan groups. They were afraid that a bad test result would be passed on, for example, by ethnicity-matched translators, while (severe) illness was perceived as something private and often seen as a taboo.

Table 6. Summary of (additional) determinants increasing the likelihood of participation in the PCs

Construct	Determinant	Ethnicity[a]	Description		Quote
1.Predisposing factors	1.Generation differences; older generation	A	Experiencing more complaints, more aware of health	➔	Q 1.1 on generation differences (Dutch lower SES): *"I think that the older you are, the sooner you would go because something is wrong, you have complaints. Look: if you're younger, you think: 'I'm healthy, I'm in the prime of my life', you don't care."*
2.Awareness factors	1.High-risk test result	A	Participating in the HRA increased awareness, the high risk test result combined with a wish for certainty would be a cue to action to go to doctor because the sooner to undertake action the better	➔	Q 2.1 on high-risk test result (Moroccan adult child): *"If I would get this and they would say: 'you have an increased risk', than I would immediately contact my GP."*
3.Motivation factors	1.Convictions; 'must'	A	There would simply be no other sensible choice than participating after receiving a high risk test result	➔	Q 3.1 on conviction of 'must' (Turkish immigrant): *"Yeah sorry, but if you don't go to the GP in that case, I think that's pretty stupid, you just have to go. Yeah sorry, but that's just how it is!"*
4.Barriers and ability factors	1.Action linkage children	T/M	Accompany their parents, translate, provide mental support or a ride		Q 4.3 on overcoming time barriers (Moroccan immigrant): *"For example, when you're in Morocco and the letter arrives, because most of the elderly spend a lot of time in Morocco, I feel that it should be possible to rearrange the appointment. I feel that this should be taken into account."*
	2.Compensation	A	Insurance coverage of PCs, medication or other wtreatment, and lifestyle changes		
	3.Overcoming time barriers	A	Person's own skills to 'make time', taking as little time as possible for PCs, and being flexible	➔	

[a] Column represents the ethnic group(s) in which determinant was most prominent: A=all groups, T=Turkish, M=Moroccan, S=Surinamese, D=Dutch

Barriers and ability factors

Turkish and Moroccan participants would again face a language barrier and ask their children for translation. The difficulty of the verbal information (i.e. health illiteracy) provided during the PCs was recognized as a problem for all groups. For the HRA, costs were mainly an issue among the Dutch groups, while this aspect was expressed among all groups when discussing PCs participation. Compensation for possible costs would be an important facilitating factor. Time concerns were also expressed (Q 4.3, Table 5), although participants felt that people should make time for PCs (Q 4.3, Table 6). For the Dutch groups this involved arranging time off from work, and for the Turkish and Moroccan groups this involved the prolonged stay in their home country during the summer vacation. In addition, during the period of Ramadan many would be reluctant, or even prohibited, to attend the PCs. Summarizing, reasons for not attending the PCs overlapped with reasons for not completing the HRA but additional reasons were notably more affective and included negative emotional responses and related coping strategies incorporating risk denial, fear about the outcome, its potential consequences (lifestyle changes and medication prescription), and disease-related stigma.

DISCUSSION AND CONCLUSION

Discussion

In this study we have identified factors influencing (non-)participation in a two-stage cardiometabolic health check among difficult-to-reach, vulnerable populations. The kind of invitation and the source was thought to influence the decision-making process, as recognized by studies in the general population (31– 33). A multi-strategy approach combining mailed letters, telephone calls, and/or especially face-to-face strategies seems useful for increasing uptake in vulnerable groups (34). Combined with an awareness campaign and/or a more community-involved GP, uptake may be further increased. Nonetheless, a good relationship with their GP and sufficient trust in the Dutch healthcare system would benefit this invitation (32, 33). In line with the literature among the general population, our vulnerable participants expected health-conscious patients to more frequently follow-up an invitation for the HRA as they would see the importance and advantages of doing so (12, 15). This contrasting a more negligent group, comprising men and individuals without health problems who would have a more negative attitude and not recognize the necessity of screening. Feeling healthy was also seen as hampering the acceptance of a high-risk HRA outcome as it would not fit the patient's illness perceptions (35). Participants also expected these negligent patients to regularly engage in denial strategies to cope with an increased risk, for example, by minimizing their personal vulnerability by comparing their own behaviour with that of others behaving in even less healthy ways (i.e. downward social comparisons), or the stereotype person at risk (36). Consequently, they would not see the purpose of further testing at the GP, which may be labelled as a 'defensive bias' (37). Negative emotional reactions were mentioned as a response to a high-risk HRA result and most prominently as a reason for nonparticipation in the PCs. Fear was also the most distinct emotional reaction and reason for non-attendance among the general population (12, 15). Others concluded that avoiding further testing is a way of managing fears caused by an increased risk and explained it as a strategy for individuals to ease the stigma and guilt associated with the perceived personal responsibility for their risk status: they wanted to postpone screening until they had made progress through lifestyle changes (38). The current study adds that refraining from further testing may follow from the wish not to be treated differently, fuelling the fear of gossip, especially among Turkish and Moroccan patients. For Turkish and Moroccan patients, the poorer command of the Dutch language would be a problem when completing the HRA, it could hinder a trusting relationship with their GP and, consequently, their PCs' attendance. The deployment of ethnicity-matched translators seems a logical solution, but may pose a problem considering the fear of gossip (passing on negative screening outcomes to others).

Strengths and limitations

Carrying out focus groups with adult children of immigrants is an innovative approach and worked best among the Turkish and Moroccan children: we obtained more extensive information because they were generally more outspoken and assertive. Focus groups with adult children of immigrant groups seem especially useful when these children are accustomed to being involved in their parents' decision-making. The results from focus groups with these adult children were verified among the immigrant groups and combined with data from the healthcare professionals. By this way of triangulation, we looked at the data from multiple angles composing a complete as possible picture. To further increase the internal validity, the design and analysis of this study were embedded in an encompassing theoretical framework, allowing room for inductively derived determinants. The I-change model seems important in explaining the decision of (non-)participation in a health check, particularly the HRA. Regarding the decision of attending the PCs, the model could be improved by adding coping determinants for dealing with an increased risk. Finally, to ensure reliability we have structurally organized the data, including audio-taping of interviews, using an analysis software program and a coding tree, keeping a log, and double-coding. Some limitations to the study should be discussed. First, we had to pre-set the number of focus groups, which led to small and diverse groups of participants. Some focus groups did not consist of the intended minimum of six participants, which could have led to less interaction between participants. These aspects may have diminished generalizability of findings. Previous studies, however, found comparable results suggesting a certain level of generalizability to other types of screening and populations. Second, although we presented inferences for one or more of the separate ethnic groups only if strongly present, they have to be interpreted with caution. Third, in the few cases the observer/notetaker had to translate misunderstandings and loss of profundity may have occurred. Fourth, participants did not have the opportunity to comment or correct the transcripts, possibly impeding internal validity of the study. Finally, participants were highly motivated to participate in the study, therefore, a selection bias might have occurred. Nevertheless, all participants verbalized potential doubts of others less willing to participate, which may have been a subtle way of ventilating their own doubts.

Conclusions

The purpose of this study was to provide an overview of informational, practical, and psychosocial factors influencing the (non-)participation in a two-stage cardiometabolic health check among difficult-to-reach, vulnerable populations. Even though similarities between determinants influencing (non-)participation in the HRA and the PCs were manifold, important differences were also noted. When considering filling out the HRA, more cognitive aspects, including rational cost–benefit considerations, were prominent. After a high-risk HRA result and the subsequent decision to (not) participate in the PCs, cognitive aspects would still play a role but more importantly would trigger negative affective responses and related coping aspects to deal with these emotions. We had expected to find distinct determinants for (non-)participation in cardiometabolic screening among non-Western immigrants and lower SES native Dutch. However, the majority of observed determinants seemed similar to determinants found in previous studies among the general population or studies focusing on cancer screening. This suggests that though perceived risk of and worries about cancer are higher than about CMD, determinants influencing the decision to participate in screening may not differ much. These determinants may not vary substantially between ethnicities except for language barriers and possibly the larger impact of gossip and taboos among Turkish and Moroccan immigrants.

Clinical implications

Findings from this study can be used to design new or adapt existing two-stage cardiometabolic health checks for vulnerable groups. Regarding the first stage, i.e. inviting people to complete a short non-invasive HRA, choice of invitation strategy seems crucial. A multi-strategy approach, including a face-to-face strategy, may be important in increasing uptake, especially when combined with an awareness campaign and/or a more community-involved GP. Written or verbal translations must be provided for non-native participants. Finally, as flawed risk perceptions and attitudes regarding screening are common, individuals should be presented with accurate information on risks and (dis)advantages of screening to support them in making informed choices about participation (32). Regarding the second stage, i.e. inviting people to attend PCs for further testing, negative emotional responses and defensive coping strategies have to be taken into account. Minimizing one's risk and feelings of personal vulnerability does not necessarily mean that high-risk individuals are not receptive to information (36). GPs or other healthcare professionals should explore these emotions and fears regarding further testing, in order to, again, support informed choices. Additionally, there is a need to take social context into account, especially since many non-Western cultures can be characterized as group cultures (36). To increase acceptance of 'being different' due to having a high-risk or CMD, it is suggested to involve family and friends in the patient's lifestyle advice and/or treatment. Additionally, the topic of cardiometabolic risk should be brought to the attention of key figures within the community, who can help eliminate some of the associated stigma and taboo (39, 40).

ACKNOWLEDGEMENTS

The authors thank all organizations for their cooperation in conducting focus groups at their locations, and the key persons in particular for recruiting participants and providing translations if necessary.

Contributors

MC, SD, WG, and AS filed the proposal for this study. The design, execution, and analysis were mainly done by IG and MC, in close collaboration with the research team. The paper was written by IG and critically revised by all authors. All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. IG is guarantor.

Funding

This study was funded by the Dutch Heart Foundation, the Dutch Diabetes Foundation, and the Dutch Kidney Foundation in a collaboration called *LekkerLangLeven* [Living nice and long], grant number 2008.20.005. The views presented in this manuscript are those of the authors and do not necessarily reflect those of the study funders.

Competing interests

None of the authors have other financial relationships with organizations that might have an interest in the submitted work.

Ethical approval

This study was approved by the Medical Ethical Committee of Leiden University Medical Center (CME-09-126).

Data sharing

Anonymized transcripts and coding tree are available from the corresponding author.

Transparency

The lead author (IG) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

APPENDIX A

Example interview protocol for native Dutch with lower socioeconomic status (SES)

Focus groups; interview protocol native Dutch lower SES

Checklist

- Name tags and markers.
- Recording equipment.
- Informed consent forms.
- Flip-over.
- Coffee, tea, and snacks.
- Gift certificates.
- Example invitations (for participation in HRA and PC).
- Yellow, pink, green, and blue post-its and pens.
- Educational materials on cardiometabolic diseases.

Opening

Facilitator and observer/notetaker introduce themselves.
Explanation about the study and reason for the choice of participants.
What is expected of the participants. It concerns opinions and experiences of the participants. Answers given are never wrong. Everyone is expected to join the discussion.
Data will be treated anonymously and confidentially, which also means: everything discussed by the group will stay within the group.
The discussion will be audio taped, transcribed, and then erased (Informed consent).
Interested in report of findings?
Duration: approximately 2 h. In between: short break with coffee/tea and snacks.
Afterwards: gift certificate (and depending on time of day: meal).
Questions?

Introduction round

Name (or pseudonym), age, family status, reason for participation.

Opening question

(1) Has anybody ever heard of a health check?
If yes: could you explain what it is?
(A) Have you ever participated in such a check?
(B) Do you know people who have participated in such a check?
(C) What was your/their experience with it?
If no: what do you think of when you hear this term?
Explanation about the Health Check, the HRA specifically.

Questions about the HRA

(2) Imagine that the GP sends an invitation to participate in a health check, how would your family react?
(A) Who opens the mail?
(B) Who would know about the invitation?
(C) Who decides what would be done with the invitation?

(3) Here I have got two example invitations for such a health check, attentively read both of them. What is your first impression?
(A) What should be included in the invitation by all means, and what should not?
(B) Did you notice anything about the formulation of the message? If necessary ‘help out’: one of them is gain framed, while the other is loss framed. What would work better?

(C) What would be the most effective way of inviting (written/ by telephone/face-to-face/other)?
(D) Additions. . .
(E) Anecdote!

(4) What would be reasons for you (or your neighbour/brother or sister/best friend) not to participate in the HRA?
(A) Any biological (physical) reasons? Would women or men be more inclined to fill out the test?
(B) Any psychological reasons, for example character traits?
(C) Would young or older people be more inclined to fill out the test?
(D) How would important others react? Would others find it important to fill out the test? Would others fill out the test?
(E) Trust in health care system/doctors/researchers?
(F) (Religious) locus of control? Do you have control over your health? Are external causes the reason for getting ill?
(G) Knowledge and awareness ('health literacy')? Publicity? Relationship with GP
(H) Communication/interaction?
(I) Emotional?
(J) Name 3 advantages.
(K) Name 3 disadvantages.
(L) Name 3 barriers which would prevent you from filling out the test.
(M) Name 3 things which would make it easier for you to fill out the test.

(5) What would be reasons for you (or your neighbour/brother or sister/best friend) to participate in the HRA?
(A) till (M) as above.
What would be solutions for the problems mentioned earlier?

Break

Questions about the PCs
Explanation about the Health Check, the PCs specifically.
(6) Again we have made two example invitations, attentively read both of them. What is your first impression?
(A) What should be included in the invitation by all means, and what should not?
(B) Did you notice anything about the formulation of the message? If necessary 'help out': one of them is gain framed, while the other is loss framed. What would work better?
(C) Would a prescheduled date and time work?
(D) Would you prefer to be approached differently for this than what we discussed about the HRA?
(E) Additions . . .

(7) What would be reasons for you (or your neighbour/brother or sister/best friend) not to participate in the PCs?
(A) Any biological (physical) reasons? Would women or men be more inclined to go to the PCs?
(B) Any psychological reasons, for example character traits?
(C) Would young or older people be more inclined to go to the PCs?
(D) How would important others react? Would others find it important to go to the PCs? Would others go to the PCs?
(E) Trust in health care system/doctors/researchers?
(F) (Religious) locus of control? Do you have control over your health? Are external causes the reason for getting ill?
(G) Knowledge and awareness ('health literacy')? Publicity? Relationship with GP?
(H) Communication/interaction?
(I) Emotional?
(J) Name 3 advantages.
(K) Name 3 disadvantages.
(L) Name 3 barriers which would prevent you from attending the PCs.
(M) Name 3 things which would make it easier for you to attend the PCs.

(8) What would be reasons for you (or your neighbour/brother or sister/best friend) to participate in the PCs?
(A) till (M) as above.
What would be solutions for the problems mentioned earlier?

(9) Would anybody like to share anything about what we discussed today, it may concern anything?

Closing

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